LEUKODYSTROPHY .org.au AUSTRALIA

newsletter / **spring 2026**

34 years ago, one woman's determination became a community!

On 17 August 1992, Sister Julie Thomas CSB OAM, together with a small team of committed volunteers and friends, officially launched the Australian Leukodystrophy Support Group, now Leukodystrophy Australia, at St Vincent's Hospital in Melbourne.

But the story began with Sr Julie's own lived experience.

After years of unexplained health and mobility challenges, Sr Julie was diagnosed with Adrenomyeloneuropathy (AMN), a type of leukodystrophy, in 1988. In 1991, she travelled to the United States as a research patient of renowned leukodystrophy specialist Professor Hugo Moser at Johns Hopkins Hospital. During that trip, she attended a United Leukodystrophy Foundation conference and saw families, people living with leukodystrophy and medical professionals coming together to share knowledge and support.

The experience left Sr Julie with what she described as a "strong feeling and urge" to create something similar in Australia.

One year later, that determination became a reality.

34 years on, Sr Julie's vision continues through Leukodystrophy Australia and our commitment to informing, supporting and connecting people impacted by leukodystrophy across Australia.

We remember Sr Julie with immense gratitude, and we thank every family, volunteer, supporter, clinician, researcher and friend who has helped carry her vision forward.

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Tribute to John Olsen OAM

We are deeply saddened to share the news that our dear friend, John Olsen OAM, passed away on Monday, 8 June. We send our heartfelt condolences and love to John's family and friends during this difficult time.

John was a truly compassionate, kind and caring man who changed many lives through his unwavering commitment to helping others. He will be greatly missed by all who had the privilege of knowing him.

Some people leave footprints wherever they go. John Olsen left them right across Australia — and in the hearts of so many in our leukodystrophy community.

John's extraordinary walks across the country were driven by love, compassion and an unwavering commitment to helping others living with leukodystrophy and disability. Through every step, he brought awareness, hope and vital support to people facing incredibly difficult journeys. His determination and spirit have inspired countless people and created a lasting legacy that will never be forgotten.

Watch **"John's Long Walk for Leukodystrophy"** here:

https://www.youtube.com/watch?v=n-mgRZ8lLms

2026 EVENTS & MEETINGS

Friday 16 October	**The Charity Challenge Golf Day** – Sydney
Saturday 24 October	**34th Annual General Meeting (AGM)** – online
Sunday 22 November	**Victoria Community Lunch Event**
Wednesday 2 December	**The Charity Challenge Golf Day** – Melbourne

Your Voice Matters. Your Membership Counts!

The essence of our organisation is our MEMBERS. By working with our members, Leukodystrophy Australia works to achieve goals that benefit all people living with Leukodystrophy.

For our awareness raising and grant submissions to government and private benefactors, our 'memberships', and our 'members lived experience' is vital.

Click here for 2026/27 Membership

Membership is free if you or a family member has leukodystrophy.

Become a Committee Member!

Are you interested in becoming a Leukodystrophy Australia Committee Member or offering your expertise? Contact Leukodystrophy Australia on **1800 141400** or **info@leuko.org.au** or visit our **website for more information**

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AGM

Leukodystrophy Australia – 34th Annual General Meeting (AGM)

Register Now

Saturday 24th October at 2pm ADST (online) (check your time zone)

As a member, you are welcome to attend our AGM.

For more information and to register for our AGM: **click here**

Leukodystrophy Australia extends our sincere thanks to **ALD Connect** for inviting our Family Advocate/ Social Worker to attend the 2026 Annual Meeting and Patient Learning Academy, taking place November 6–7, 2026 in Salt Lake City, Utah.

The conference will provide many opportunities for connecting with ALD Connect staff, specialists, researchers, families and advocates from around the world to share knowledge, strengthen international collaboration and learn from experiences. In particular, with newborn screening for ALD preparing to commence in Australia, insights from countries with established screening programs will help inform and support its introduction here.

Our Family Advocate has also been invited to provide a presentation on the work of Leukodystrophy Australia at this conference.

If you have any questions, topics or information you'd like explored while attending, please contact **Claire** on **1800 141 400.**

rare voices AUSTRALIA

Rare Voices Australia Summit Melbourne 2026

Rare Voices Australia will host their biennial National Rare Disease Summit in Melbourne this November, bringing together key stakeholders in the rare disease sector. The 2026 theme ***Equity: Gaps and Opportunities***, invites the sector to examine progress, identify persistent inequities, and explore how existing system strengths can be leveraged to improve equitable access to education, care and support and research.

Our Family Advocate looks forward to representing Leukodystrophy Australia at this summit and continuing to advocate for the collective needs of our leukodystrophy community.

Childhood Dementia Initiative

Leukodystrophy Australia is grateful to the Childhood Dementia Initiative for the opportunity for parents and carers of children with leukodystrophies to participate in their Long Table consultation to inform government and improve health systems in Victoria and Tasmania.

This provided a respectful and supportive space where parents and carers could openly share their lived experiences and make suggestions for health system improvements. During the consultation process, families were encouraged by the genuine commitment to improving care for those affected by childhood dementia across Victoria and Tasmania.

Thank you to the parents and carers who participated from across Victoria and Tasmania.

Lived experience shaping newborn screening and better health outcomes for X-ALD

Leukodystrophy Australia is grateful for the opportunity for our lived experience x-ALD community to have contributed to this research.

This 2-page public publication presents a summary of the ethical considerations and social acceptability of newborn screening for X-linked adrenoleukodystrophy (X-ALD) in females—and highlights the vital role of lived experience in shaping understanding, policy and care.

Ethical implications and social acceptability of

X-ALD SCREENING IN FEMALE NEWBORNS

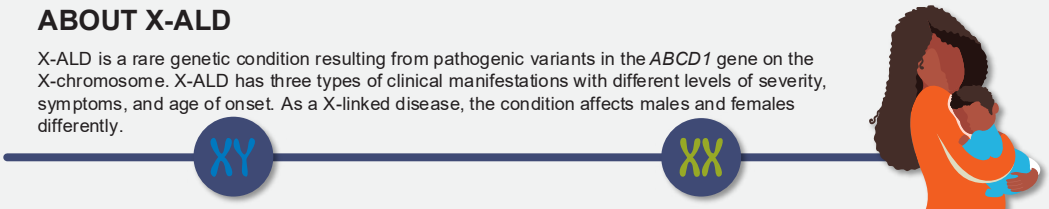
Australia's newborn bloodspot screening (NBS) programs identify newborn babies at risk of developing a serious condition.

Adding new conditions to NBS programs follows rigorous assessment via the decision-making pathway. This involves evidence reviews, health technology assessments, expert input, and consideration of alignment to the NBS National Policy Framework criteria. As part of this assessment process, advice is provided by the Medical Services Advisory Committee (MSAC) to support Australian Health Ministers to consider conditions for screening.

The purpose of this document is to present a concise summary of the work undertaken examining the ethical considerations and social acceptability of screening X-linked adrenoleukodystrophy (X-ALD) in female newborns.

ABOUT X-ALD

X-ALD is a rare genetic condition resulting from pathogenic variants in the *ABCD1* gene on the X-chromosome. X-ALD has three types of clinical manifestations with different levels of severity, symptoms, and age of onset. As a X-linked disease, the condition affects males and females differently.



MALES are **more likely** to be **affected by** X-ALD as they have one X-chromosome and one Y-chromosome.

FEMALES have two X-chromosomes, so their unaffected X-chromosome can help to **counter the affected X-chromosome**.

WHY WAS THIS WORK CONDUCTED?

MSAC provided advice that supported the inclusion of X-ALD in Australian NBS programs for all newborns. Considering this, in late 2024, Australian Health Ministers agreed to add X-ALD to Australia's NBS programs for male newborns, requesting further examination of the ethical considerations and social acceptability of screening female newborns.

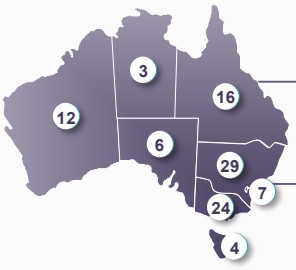
Following completion of this work, on 12 December 2025, Ministers agreed to also screen female babies for X-ALD within NBS programs. All governments have agreed that screening will begin within 2 years of health ministers' decision to add a condition.

METHODOLOGY

The work to explore ethical considerations and social acceptability of screening for X-ALD in female newborns involved consultations across Australia and an evidence review:

- **101** Members of the **general public** consulted through focus groups
- Interviews with **people with lived experience** of X-ALD **24**
- **17** Interviews with **expert stakeholders**
- **REVIEW OF INTERNATIONAL PEER REVIEWED LITERATURE**

GENERAL PUBLIC CONSULTATION

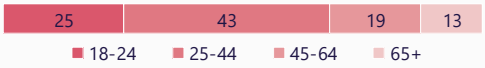


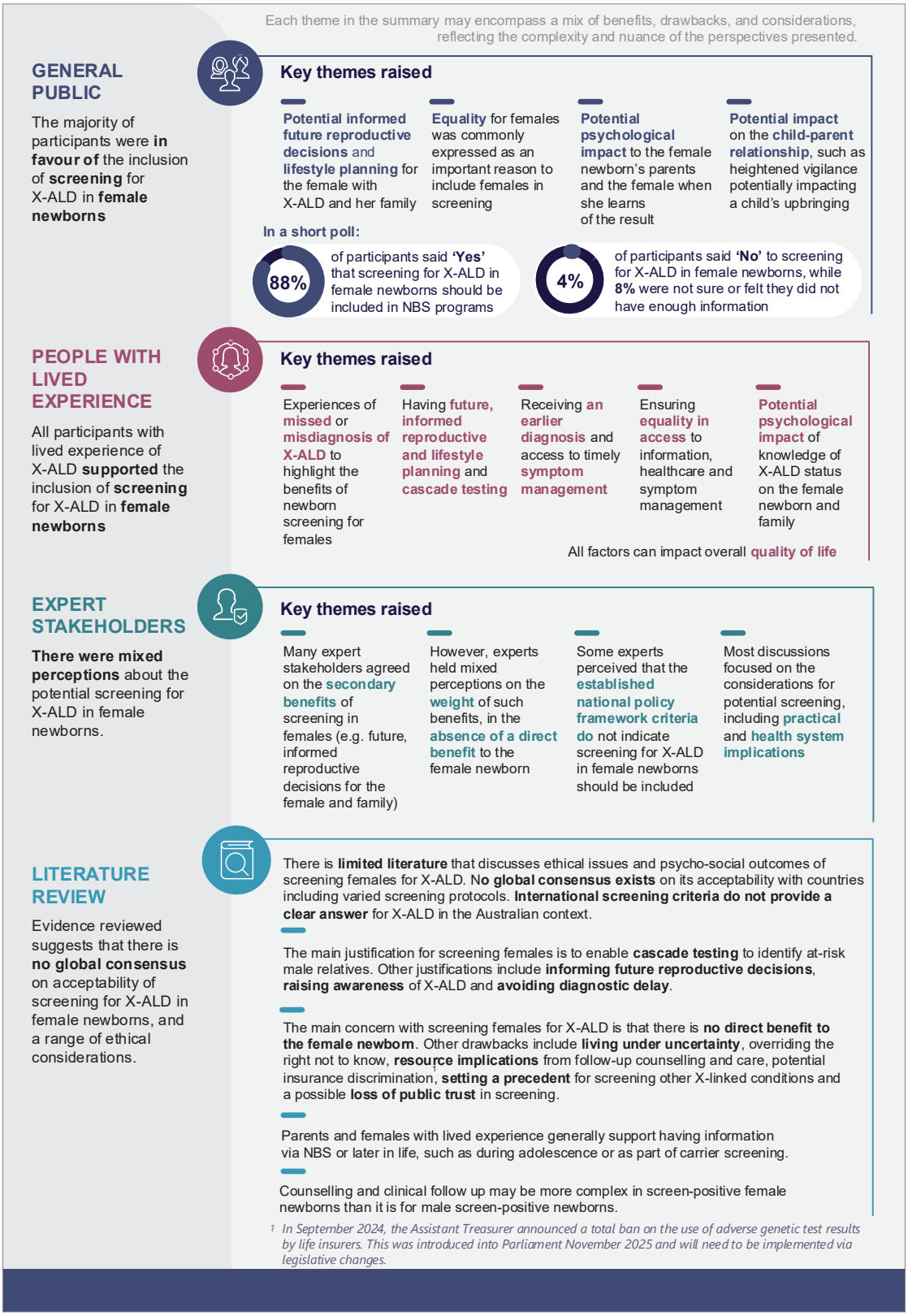
15 Focus groups

Female 55%

Male 45%

Age distribution (%)





Read more here:

https://www.health.gov.au/.../x-linked...

Newborn screening for x-ALD is expected to commence later this year or early 2027. We will keep you updated as more information becomes available.

Save the Date – Victoria!

We're excited to announce that Leukodystrophy Australia is planning to host a Lunch on **Sunday, 22 November** in Melbourne *(accessible venue to be confirmed)*.

Leukodystrophy Australia lunch events bring together people living with leukodystrophy, along with their families and support networks. It's a chance to share a meal, make meaningful connections, and reduce the isolation that many experience.

As a small charity, opportunities like these are only possible thanks to grants, donations, and fundraising. Support will be available to assist those in regional areas to attend.

Save the date now—we'd love to see you there!

Please contact Claire or Jane to ensure your records are up to date so that you receive an invitation.

Contact 1800 141 400
or 0418 790 059
advocate@leuko.org.au

EVENTS

The Charity Challenge Golf Day **Sydney** Friday 16th October

Please join us for the Leukodystrophy Charity Challenge Golf Day – Sydney, at the picturesque Long Reef Golf Club on Friday 16th October (morning tee-off, followed by lunch). Format will be 4 person Ambrose.

It's always a fantastic day on the course – and every swing helps raise vital funds in support of individuals and families living with leukodystrophy. We're also offering a Beginners Clinic option for those newer to the game.

Register now: Leukodystrophy Charity Challenge Golf Day – Sydney

If you can't make the Sydney event, you can still support it by sharing details with friends and colleagues, donating prizes or sponsorships, or by making a direct contribution to Leukodystrophy Australia: **Donate Here**.

The Charity Challenge Golf Day **Melbourne** Wednesday 2nd December

Woodlands Golf Club – Registration: **Leukodystrophy Charity Challenge Golf Day - Melbourne**. Format will be team Stableford.

If you have any questions about the Sydney or Melbourne events contact:

Earl Schonberger
0477 550 977 (President – Leukodystrophy Australia)

Gary Dawson OAM
smokey@bullantsports.com or **0412 600 062**

Matthew Laverty OAM
matthew@lavertygolf.com.au or **0418 161 199**

The Charity Challenge
www.thecharitychallenge.com

X-ALD Newborn Screening has commenced in Western Australia!

Leukodystrophy Australia is pleased to share that newborn screening for X-linked Adrenoleukodystrophy (X-ALD) has commenced in Western Australia. This is an important milestone for families affected by X-ALD.

It is expected that other States and Territories will follow by late 2026 to early 2027.

Early detection of X-ALD is vital, allowing for appropriate monitoring for adrenal insufficiency and cerebral ALD. For boys and men identified with X-ALD, regular MRI is essential for identifying early cerebral disease, when treatment may be most effective.

Every baby identified early is an opportunity to monitor, intervene when necessary, and potentially improve outcomes. See information released by the Western Australia Department of Health: **https://www.health.wa.gov.au/.../X-linked...?**

If you are the parent of a baby identified with X-ALD through newborn screening, please contact Leukodystrophy Australia for information, support and connection.

Contact Claire or Jane:
Tel: **1800 141 400** or **0418 790 059**
Email: **advocate@leuko.org.au**

Leukodystrophy Australia – Types of Leukodystrophy

https://leuko.org.au/leukodystrophy/leukodystrophy-types/

Leukodystrophy Australia is working to progressively develop and maintain a comprehensive and up-to-date list of known leukodystrophies and leukoencephalopathies. The current resource includes more than 70 conditions, with information organised by condition name, associated gene, alternative names, abbreviation and links to further information. Many of these links currently direct users to established external clinical, research and rare-disease resources. Over time, we aim to further develop this resource through a more formalised and consistent approach to terminology, classification, supporting information, source selection and review. Our goal is for the list to evolve into a trusted, regularly maintained reference resource for people living with leukodystrophy, families, clinicians, researchers and others seeking reliable information.

If you or anyone you know would like to be involved in this project, please reach out to Earl Schonberger on **0477 550 977**.

Women with ALD and AMN: Recognise, Understand, Support!

Since 1984, research has shown that women with ALD can develop symptoms of Adrenomyeloneuropathy (AMN) just as men do! Unfortunately, this knowledge and research is still not widely known.

Read the research article **"Disease Burden in Female Patients With X-Linked Adrenoleukodystrophy"** here:

https://aldconnect.org/.../Disease-Burden-in-Female-ALD...

Leukodystrophy Australia was built on the legacy of Sr Julie who lived with the impact of ALD in her family while experiencing decline and symptoms of AMN.

Greater awareness leads to earlier recognition of symptoms, better understanding and improved support for women living with ALD.

With ALD newborn screening soon to commence, more women will be identified and will need access to appropriate clinical care, understanding and support.

Watch this YouTube presentation by Dr Yedda Li on the symptoms that may affect women. Video Link:

https://www.youtube.com/watch?v=f1MmDdEwGQ0

Rare Voices Leukodystrophy Information Page

Rare Voices Australia has added details on Leukodystrophy (Group of conditions) to its rare disease directory.

https://www.rareportal.org.au/rare-disease/leukodystrophy/

X-linked adrenoleukodystrophy (X-ALD) and **Alexander disease** are individually detailed.

Thank you to Rare Voices and experts Dr Michel Tchan and Dr David Manser for their co-development of this resource.

If you would like to share your personal journey living with leukodystrophy, you can do so here: **https://rarevoices.org.au/share-your-story/**

Stories may be considered for publication on the RARE Portal, like **Ryan's Story**

Childhood Dementia Initiative Parent Knowledge Network

Leukodystrophy Australia is pleased to share the Childhood Dementia Initiative Parent Knowledge Network – a FREE monthly online program designed to connect families, share experiences and build community support.

More than 20 leukodystrophies are recognised as childhood dementia conditions, including adults diagnosed as children, living with a progressive, life-limiting condition.

To learn more and register: **https://www.childhooddementia.org/parent-knowledge-network**

Practical resources are also available, including medical summary templates and appointment checklists **https://www.childhooddementia.org/families.../family-guide**

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Sibling Research Survey being conducted by UNSW Sydney, Siblings Australia Inc, Genetic Alliance Australia, Belongside Families:

We want to hear from teenage siblings in Australia:

Growing up alongside a brother or sister with a long-term condition often builds siblings' empathy, resilience, and a deep sense of care for their family. But it can also raise big questions and emotions that they don't always have support to work through. When reliable information and support isn't easy to find, siblings may turn to social media or AI tools for answers and not everything they find there is accurate or helpful.

Right now, there isn't enough research on how siblings in Australia find information and access support, which makes it hard to know what kind of resources would help. We want to change that. By understanding where siblings look for information, we can build more resources designed around siblings' real experiences.

UNSW SYDNEY

Siblings australia inc

genetic alliance australia

Belongside Families

We want to hear from siblings of a brother or sister with a long-term health condition

What counts as a long-term condition? Any illness, disability, or diagnosis that lasts a long time e.g., Fragile X Syndrome, cerebral palsy, cystic fibrosis, Down Syndrome, and many others.

Why? We want to understand where siblings find information about their brother or sister's condition and support, and what kinds of information they are looking for.

Who can take part?

- Siblings aged **12 to 18 years**
- Living in Australia
- Has a brother or sister with a long-term health condition

What's involved?

- Online survey (10 minutes)

Scan the QR code to access the survey

Survey responses are completely private and anonymous.
Responses cannot be seen by anyone outside of the research team.

For questions, contact **Maddison Smith** (PhD Candidate)
maddison.c.smith@unsw.edu.au
This study was approved by the University of New South Wales Human Research Ethics Committee (10937)

H-ABC Study:

Do you or someone you know have H-ABC? We'd love your help!

The Translational Centre for Speech Disorders (Australia) is a conducting a research study to better understand speech patterns in children and adults with H-ABC (Hypomyelination with Atrophy of the Basal Ganglia and Cerebellum).

Participation involves:

- A short online survey to complete
- 15min speech task

To learn more contact:

Claire at Leukodystrophy Australia on **0418 790 059** or **advocate@leuko.org.au**

Or scan the QR or contact Ruth Braden at: **ruth.braden@mcri.edu.au**

murdoch children's research institute

THE UNIVERSITY OF MELBOURNE

geneticsofspeech.org.au

Translational Centre for Speech Disorders
Centre of Research Excellence

Speech and Language in individuals with H-ABC:

An international study

We are running a project looking at speech and language outcomes in individuals aged 6 months to adulthood with Hypomyelination with Atrophy of the Basal Ganglia and Cerebellum (H-ABC).

By improving our understanding of speech and language in this condition, we hope to improve prognoses, better identify those in need of support and develop more targeted strategies.

We are looking for individuals:

- Aged 6 months to adulthood
- Confirmed to have a pathogenic *TUBB4A* variant by genetic test
- Who are verbal or minimally-verbal

What is involved?

- Completing online surveys about speech and language skills, and health and medical history
- Completing a quick 15 minute speech task from home

About us

The Translational Centre of Research Excellence for Speech Disorders examines speech and language in individuals with rare genetic conditions.

We are trying to better understand the strengths and difficulties of communication in children with rare genetic syndromes. Our longer-term aim is to help develop better targeted therapies.

GET IN TOUCH!

If you or someone you know may be interested in helping with this research, we would love to hear from you. Scan the QR code or Contact us at: ruth.braden@mcri.edu.au

Translational Centre for Speech Disorders
Murdoch Children's Research Institute
50 Flemington Road, Parkville VIC 3052
geneticsofspeech@mcri.edu.au
v1.13.09.2023

This project has been approved by the Royal Children's Hospital Human Research Ethics Committee (RCH HREC Reference Number 37353)

Companion Card – Community access matters

For people living with leukodystrophy, going to events, attractions or family outings can sometimes require the support of a companion.

The Companion Card helps eligible people with significant and permanent disability access the community with the support they need.

At participating venues, the card allows a companion to attend without the cost of an extra ticket.

This can make a meaningful difference for families, carers and people living with lifelong disability.

Find out more: **https://www.health.gov.au/our-work/companion-card?language=en#about-the-companion-card**

Palliative Care

Palliative care teams help manage symptoms so individuals and families can hold onto the moments that matter. With the right support, families feel less alone, decisions are respected, and care stays focused on what matters most.

Advice, tools and support at palliativecare.org.au

Watch this YouTube video: **https://www.youtube.com/watch?v=hR81mQZCZXE&t=1s**

Children & Young Adult Respite Hospices

Australia has several specialised hospices that support children and young adults with life-limiting conditions — giving families a place to come together to rest, recharge and feel cared for.

QLD – Hummingbird House
https://hummingbirdhouse.org.au/

NSW – Bear Cottage
https://bearcottage.schn.health.nsw.gov.au/

NSW – Adolescent & Young Adult Hospice

VIC – Very Special Kids
https://vsk.org.au/

SA – The Beach House
https://wchfoundation.org.au/the-beach-house/

WA – Sandcastles New hospice opening late 2026
https://sandcastles.org.au

Adolescent and Young Adult Hospice – Manly, NSW

Based in Sydney, the Manly Adolescent and Young Adult Hospice (AYAH) is Australia's first dedicated respite service for young adults with life-limiting illness. This no-cost service is for over 16-year-olds, offering respite, end-of-life care, symptom management and care coordination support. NSW residents are given preference, however - if capacity allows - consideration may also be given to families living interstate.

For more information **see flyer**; email: **nslhd-ayahmanly@health.nsw.gov.au** or **AYAH! Virtual Tour** (load time may vary)

Rare Voices Australia Tool Kit – Practical Resources

Rare Voices Australia has developed the Rare Disease Disability Toolkit. This nationally codesigned Toolkit of practical resources, is available on the Rare Voices Australia website: **https://rarevoices.org.au/rare-disease-disability-project/rare-disease-disability-toolkit/**

There are 3 Guides with practical checklists and templates to support you with Health, NDIS and Community access – air travel

- **HEALTH**
- **NDIS**
- **COMMUNITY (Air Travel)**

More resources will be added to the Toolkit between now and December 2026.

If you have any feedback on these resources or additional information you would like to see included, please contact Claire on **0418 790 059** or Rare Voices Australia.

When you've got to go, you've got to go!

Finding a loo fast is stressful - and even more urgent when accessible bathrooms are limited. Using this National Public Toilet Map may make it a little easier

toiletmap.gov.au

Discover accessible national parks and trails near you!

Everyone deserves to enjoy nature — explore, connect, and adventure outdoors.

Visit: **https://ow.ly/HMQ450X5oyn**

Need an accessible Changing Place this website might help.

https://changingplaces.org.au/find

Accessible Beaches near you:

https://accessiblebeaches.com/beach-directory

This is Your Space

Do you have a story to tell or something to share in the next Leukodystrophy Australia newsletter or on our social media.

We would love to hear from you!

Sharing your journey or ideas supports others and lets them know they aren't alone!

In Memory of

Leukodystrophy Australia expresses its sincere condolences to individuals and families who have lost loved ones to leukodystrophy. We think of you and are here if you need support.

Stay in Touch

Contact us to make sure your records are up to date.

For information, support, connection and advocacy:

Contact Claire or Jane @ Leukodystrophy Australia

1800 141 400 or **0418 790 059**

info@leuko.org.au or **advocate@leuko.org.au**

For afterhours support:

Lifeline **(13 11 14)** | 13 YARN **(13 92 76)** | Kids Helpline **(1800 55 1800)**

MensLine Australia **(1300 78 99 78)**